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## Physical activity assessment in cystic fibrosis: A position statement

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Review

# Physical activity assessment in cystic fibrosis: A position statement CrossMark

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## Abstract

**Background:** The aim of this position statement was to inform the choice of physical activity tools for use within CF research and clinical settings. **Methods:** A systematic review of physical activity tools to explore evidence for reliability, validity, and responsiveness. Narrative answers to “four key questions” on motion sensors, questionnaires and diaries were drafted by the core writing team and then discussed at the Exercise Working Group in ECFS Lisbon 2013.

**Results and summary:** Our current position is that activity monitors such as SenseWear or ActiGraph offer informed choices to facilitate a comprehensive assessment of physical activity, and should as a minimum report on dimensions of physical activity including energy expenditure, step count and time spent in different intensities and sedentary time. The DigiWalker pedometer offers an informed choice of a comparatively inexpensive method of obtaining some measurement of physical activity. The HAES represents an informed choice of questionnaire to assess physical activity. There is insufficient data to recommend the use of one diary over another. Future research should focus on providing additional evidence of clinimetric properties of these and new physical activity assessment tools, as well as further exploring the added value of physical activity assessment in CF.

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## 1. Introduction

The World Health Organisation recognises the important role of physical activity in health and prevention of non-communicable disease, and has published global recommendations aimed at national policy makers [1]. Physical activity has important health benefits in chronic respiratory disease as well as in the general population. For the purposes of this Position Statement on Physical Activity Assessment in patients with Cystic Fibrosis (CF), physical activity is defined as “any bodily movement produced by skeletal muscles that requires energy expenditure” [1].

People with CF spend less time performing moderate to vigorous intensity activity than their healthy peers and overall physical activity in CF declines with age, similar to healthy populations [2]. Increased activity levels have been linked to improved fitness [3–5]. Physical fitness has been associated with decreased mortality in CF [6–8]. Increased physical activity is associated with a slower rate of decline in lung function in CF [9,10] and conditioning may, at least in part, preserve lung function [5,11–13]. Finally, high levels of physical activity have been linked to a higher bone mineral density [14] and higher health-related quality of life [15]. Therefore, as physical inactivity is an important factor in the progression of morbidity and mortality in CF and physical activity has multiple benefits, it seems reasonable to hypothesise that there is value in assessment of physical activity levels in people with CF.

We surveyed a convenience sample of CF centers which primarily consisted of centers who had participated in the ECFS Exercise Testing Consensus Survey ([https://www.ecfs.eu/ecfs\\_exercise\\_wg](https://www.ecfs.eu/ecfs_exercise_wg)). The survey found that whilst physical activity assessment was considered important, physical activity assessment tools are inconsistently used in CF centers. It is important that the physical activity tools are standardised and have good clinimetric properties. In research this will help ensure that study results are valid and will facilitate comparison between studies e.g. in meta-analyses. In clinical practice this will ensure clinicians obtain useful information about their patients as well as inform treatment decisions on physical activity.

The aim of this position statement was to inform the choice of physical activity tools for use within CF research and clinical settings to facilitate physical activity measurement.

### 1.1. Methods

To achieve this aim, it was agreed that two parallel strands of work would be conducted:

#### 1.1.1. Strand 1

Strand 1 consisted of a systematic review of the clinimetric properties (reliability, validity, and responsiveness) of physical activity tools using methods adopted from ECFS Research in Nursing and Allied Health Professions Working Group and ECFS Clinical Trials Network [16,17].

Studies on paediatric ( $\leq 12$  yrs), adolescent (13–17 yrs) and adult populations ( $\geq 18$  yrs) in CF were targeted. The search was performed from inception of the databases to December 2013. A systematic search of the following databases was undertaken: MEDLINE, EMBASE and PubMed using relevant search terms e.g. cystic fibrosis AND activity OR habitual activity OR questionnaires OR motions sensors OR diaries. A range of specific motion sensors, questionnaires and diaries were also searched for, these included commonly used tools and also all tools identified in the survey (more details in the online supplementary data). “In house” questionnaires and diaries (i.e. no published questionnaire or diary could be sourced) were excluded from the systematic review.

Reference lists of review articles were also reviewed to identify any additional studies. Data that provided evidence of clinimetric properties (reliability, validity, and responsiveness) of physical activity motion sensors, questionnaires and diaries are summarised in Tables 1 and 2 (full data tables are presented in the online supplementary data). We also explored the relationship between each physical activity motion sensor, questionnaire/diary, and outcome measures used in clinical practice and research.

Table 1

Studies providing evidence of clinimetric properties for motion sensors (full data tables are presented in the online supplementary data).

	Reliability	Convergent validity	Discriminate validity	Correlation with other outcomes	Responsiveness
SenseWear	None	Evidence of correlation with indirect calorimetry <sup>a</sup> , manual steps count <sup>a</sup> , and the EAR monitor <sup>a</sup> [18,19]	Able to discriminate between CF and healthy. <sup>a</sup> Within CF able to discriminate between exacerbation and stable patients. <sup>a</sup> [2,20]	Evidence of significant correlation with exercise capacity <sup>a</sup> , strength <sup>a</sup> , bone mineral density <sup>a</sup> , kyphosis <sup>a</sup> , and lung function <sup>a</sup> [2,20–22]	Evidence of responsiveness to IVAB <sup>a</sup> . [18,20,23]
ActiGraph	Evidence of responsiveness to IVAB <sup>a</sup> . [24,25]	Evidence of correlation with the HAES and the 7 day PAR questionnaires and the Bratteby activity diary <sup>a, b, c</sup> [24,25]	Within CF able to discriminate between gender <sup>a, b, c</sup> and disease severity <sup>b, c</sup> [15,24]	Evidence of significant correlation with exercise capacity <sup>a, b, c</sup> [3]	Evidence of responsiveness to a physical conditioning program <sup>a, b, c</sup> [5]
RT3 (plus TriTrac, earlier version of RT3)	None	None	[26]	None	TriTrac—evidence of responsiveness to IVAB <sup>b, c</sup> [27]
Caltrac	Reliable over 3 points in time <sup>b, c</sup> [28]	Evidence of correlation with the LSI monitor <sup>b, c</sup> [28]	None	None	None
Large Scale Integrated Motor Activity Monitor: LSI	Reliable over 3 points in time <sup>b, c</sup> [28]	Evidence of correlation with Caltrac monitor <sup>b, c</sup> [28]	None	None	None
e-AR	None	Evidence of correlation with SenseWear <sup>a</sup> [18]	None	None	None
DigiWalker	None	None	None	Evidence of significant correlation with step rate/count and respiratory symptoms diary and lung function <sup>a, b</sup> [29]	Evidence of responsiveness to IVAB <sup>a, b</sup> [29]

<sup>a</sup> Adults.<sup>b</sup> Adolescents.<sup>c</sup> Children.

Table 2

Studies providing evidence of clinimetric properties for questionnaires and diaries (full data tables are presented in the online supplementary data).

	Reliability	Convergent validity	Discriminate validity	Correlation with other outcomes	Responsiveness
Habitual Activity Estimation Scale (HAES)	Reliable over two points in time <sup>a, b, c</sup> [25]	Evidence of correlation with activity monitors (Sensewear and Actigraph) <sup>a, b, c</sup> and diaries (Boucher and Bratteby) <sup>a, b, c</sup> Significant difference between activity in child vs. parent versions of HAES [9,21,24,25,30]	Within CF able to discriminate between responders and non-responders to an exercise programme <sup>b, c</sup> [31]	Significant correlation with exercise capacity, body mass and lung function <sup>b, c</sup> [9,10,30]	Evidence of responsiveness to training programmes <sup>b, c</sup> [11,31]
Baecke Questionnaire	None	None	None	Evidence of significant correlation with bone mineral density and energy intake <sup>a</sup> [32,33]	None
Kriska Modifiable Activity Questionnaire	Reliable over three points in time <sup>c</sup> [28]	Evidence of correlation with activity monitor (Caltrac, LSI) <sup>b, c</sup> and with physical activity questionnaire (Harvard Alumni) <sup>b, c</sup> [28]	Able to discriminate between CF vs healthy <sup>b, c</sup> [34]	Significant correlation with exercise capacity and lung function <sup>b, c</sup> [34]	None
Physical Activity Status Questionnaire (PAS-Q)	None	None	Able to discriminate between CF and healthy <sup>a</sup> Within CF able to discriminate between different fat free mass, different lung function <sup>a</sup> [35–37]	Evidence of significant correlation between lung function <sup>a</sup> and bone mineral density <sup>a, b</sup> [35,36,38]	None
Harvard Alumni Survey	Evidence of reliability over 3 time points <sup>c</sup> [28]	Evidence of correlation with activity monitors (Caltrac) <sup>b, c</sup> and with physical activity questionnaires (Kriska Modifiable Activity Questionnaire) <sup>b, c</sup> [28]	None	None	None
Physical Activity Questionnaire for Children (PAQ-C)	None	None	Able to discriminate between CF and healthy <sup>c</sup> [39]	None	None
Lipid Research Clinics Questionnaire (LRC)	None	None	None	Evidence of significant correlation with exercise capacity <sup>a, b</sup> [24]	None
7-Day Physical Activity Recall (Interview) (7-Day PAR/Five City Project)	None	Evidence of correlation (Actigraph) <sup>a, b, c</sup> [24]	None	Evidence of significant correlation with bone mineral density and with urinary Pyridinium Crosslinks <sup>a</sup> [40]	None
30-day Physical Activity Recall (Interview) (30-Day PAR)	None	None	Within CF able to discriminate between gender <sup>b</sup> [41]	Significant correlation with exercise capacity <sup>b</sup> [41]	Evidence of responsiveness to training programme <sup>b</sup> [41]
International Physical Activity Questionnaire (IPAQ)	None	None	Able to discriminate between CF and healthy <sup>a</sup> [42]	Evidence of significant correlation with lung function <sup>a</sup> [42]	None
Bouchard Diary	None	Evidence of correlation with HAES <sup>b, c</sup> [9]	Able to discriminate between CF and healthy <sup>b, c</sup> Within CF able to discriminate between CF PI and PS <sup>b</sup> [15]	Evidence of significant correlation with exercise capacity, quality of wellbeing and body mass percentile <sup>a, b</sup> [15]	None
Bratteby Diary	Reliable over two points in time <sup>a, b, c</sup> [25]	Evidence of correlation with activity monitors (Actigraph) <sup>a, b, c</sup> and physical activity questionnaires (HAES) <sup>a, b, c</sup> [25]	None	None	Responsive to inpatient training <sup>c</sup> [43]

<sup>a</sup> Adults.<sup>b</sup> Adolescents.<sup>c</sup> Children.

### 1.1.2. Strand 2

In strand 2 narrative answers to “four key questions” on the use of motion sensors, questionnaires and diaries in research and clinical practice were drafted by the core writing team and then discussed at the Exercise Working Group in ECFS Lisbon 2013. Following feedback from the Exercise Working Group the answers were revised and finalised:

1. Do motion sensors/questionnaires/diaries have the potential to be used within clinical practice?
2. Do motion sensors/questionnaires/diaries have the potential to be used as an outcome measure in research?
3. What output should be reported from motion sensors, questionnaires and diaries?
4. What is an important treatment effect for motion sensors, questionnaires and diaries?

A draft manuscript summarising the results of Strand 1 and 2 was circulated to the exercise working group for review and revised until group consensus was achieved. Subsequently, the manuscript was reviewed by the ECFS Board.

## 1.2. Results

### 1.2.1. Strand 1

Data extracted as part of this review included dimensions of physical activity i.e. step counts, time spent being physically active (often broken down into different intensities and different time periods) and energy expenditure. The clinimetric properties of physical activity assessment tools have not been evaluated consistently between studies in CF. This makes it difficult to compare tools or combine the results of different studies.

### 1.3. Motion sensors

A summary of the clinimetric properties of motion sensors used in CF is presented in Table 1 and full data tables are presented in the online supplementary data. A larger proportion of motion sensor data is available in adults with CF compared to adolescents and children. There was a general lack of consistency between physical activity assessed by motion sensors compared to questionnaires/diaries.

The SenseWear, ActiGraph and DigiWalker have the most data supporting their clinimetric properties. Of these three only the Actigraph has data on reliability. Generally for the SenseWear and ActiGraph monitors, there is evidence of convergent validity, i.e. correlation between these monitors and other physical activity tools; and there is evidence of discriminate validity, i.e. these monitors are able to discriminate between groups that are known to differ, including CF versus healthy, between groups of people with CF with different phenotypes or stable vs unstable states. There has been exploration of the relationships between physical activity with the SenseWear ActiGraph, and DigiWalker and other clinical outcome measures in CF. There is some evidence indicating a positive correlation between physical activity and measures of lung function, exercise capacity, respiratory symptoms and bone mineral density. The SenseWear, ActiGraph and DigiWalker have data demonstrating responsiveness.

### 1.4. Questionnaires/diaries

A summary of the clinimetric properties of physical activity questionnaires and diaries used in CF is presented in Table 2 and ECFS website. Some studies did not provide sufficient detail about the assessment tools evaluated (e.g. in-house questionnaires) and these studies were excluded. For many of the questionnaires, information has been converted into estimates of energy expenditure (e.g. kilocalories, METs) or some other summary measure that can be used to categorise participants by their physical activity level. There was a general lack of consistency between different questionnaires/diaries and between questionnaires and monitors or diaries.

With regard to the clinimetric properties of questionnaires, the HAES has the most available data. It has data on reliability. There is evidence of convergent validity, i.e. correlation between the HAES and activity monitors and diaries. and there is evidence of discriminate validity, i.e. the HAES is able to discriminate between groups of people with CF (responders as and non responders to an exercise programme) There is some evidence indicating a positive correlation between the HAES and measures of lung function, exercise capacity, and body mass. The HAES has data demonstrating responsiveness.

There are only two diaries, the Bouchard and the Bratteby, each with some evidence of some clinimetric properties.

### 1.4.1. Strand 2

Narrative answers to the “four key questions” on motion sensors, questionnaires and diaries were collated and are summarised below.

1. Potential to use motion sensors, questionnaires and diaries within clinical practice. Motion sensors, questionnaires and diaries have the potential to be used within clinical practice; however there are some specific considerations for each tool. *Motion sensors.* An important consideration for the choice of physical activity monitor should be the purpose for which the data will be used. Whilst sophisticated activity monitors eliminate the problems of subjective assessment of physical activity (such as poor memory and biased self-reporting), they are more costly and analysis of data output can be a time burden for patients and staff. Technical skills are required to analyse and interpret the data; and use the data appropriately to individualise physical activity advice and monitor change. Future versions of the monitors and software may improve the feasibility of incorporation of motion sensors into busy clinics. Additionally many of the systems do not give direct user feedback on current activity levels which might be important for motivation. Pedometers offer a less costly alternative but usually do not facilitate in-depth assessment of activity patterns. Often simple step count may be sufficient for assessing baseline levels of activity, monitoring change and may also serve as a motivational tool.

*Questionnaires.* It is important to consider that questionnaires measure the perception of individual physical activity, or a caregiver-reported child's physical activity; however they do not measure the ability of the person to be physical active, or



their perceptions of symptoms during physical activity. Questionnaires are also useful as a screening tool to identify those that may require advice about physical activity and facilitate discussion on physical activity patterns and goal setting. The use of electronic scoring systems facilitates scoring and interpretation. Questionnaires can be influenced by many other factors and do not always relate accurately to objective physical activity assessment. It is also not possible to use questionnaires to provide detailed information on physical activity levels or detect differences within individual patients over time.

*Diaries.* Their use is likely to be focused on facilitating discussion of physical activity patterns, to facilitate self-monitoring, explore adherence, as an aide-mémoire, as a motivational tool, and goal setting. Where possible, a standardised diary should be used in preference to an in-house diary. Diaries can be influenced by many other factors particularly inaccurate completion and do not always relate accurately to objective physical activity assessment. It is also not possible to use diaries to provide detailed information on physical activity levels or detect differences within individual patients over time.

## 2. Potential to use motion sensors questionnaires and diaries as outcome measures in research

*Motion sensors.* Motion sensors have the potential to be used in epidemiological research and as primary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF. More research may need to be conducted in CF to explore the relationship between physical activity and true clinical endpoints (i.e. how the patient feels, functions or survives and detection of a tangible benefit for the patient). Establishing this link would raise the profile of physical activity as an outcome measure in other therapeutic trials. The use of motion sensors in multicenter clinical trials would be facilitated by efforts towards standardisation (e.g. agreement on most important physical activity dimensions, standard operating procedures for performance of the measurement and methods of analysis; training; central quality control and over reading). It is also important to achieve consensus on how to report output from motion sensors in terms of both units and cut-off categories.

*Questionnaires.* Questionnaires have the potential to be used in epidemiological research. As they have high variability they are more suited to being secondary endpoints rather than primary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF.

*Diaries.* We do not recommend the use of diaries as primary or secondary endpoints in studies investigating the efficacy of exercise/physical activity interventions in CF. However, they may prove to be beneficial in exploring motivation, and adherence to the prescribed intervention

## 3. Reporting of outputs from motion sensors, questionnaires and diaries.

*Motion sensors.* There are many aspects of physical activity that can be measured and no single dimension comprehensively captures all aspects of physical activity. In order to expand our understanding of physical activity it would be

advantageous to report on the full range of physical activity dimensions available with each device. At a minimum the exercise working group propose that this should include dimensions of physical activity including energy expenditure, step count, time spent in physical activity of different intensities, and time spent sedentary. Caution should be used when interpreting energy expenditure data in CF. There are some studies exploring the validity of physical activity monitors to measure energy expenditure e.g. SenseWear [18,19]. The algorithms used to calculate energy expenditure assume that the energy expenditure required to perform these activities is uniform across populations (health and disease) and this is not the case. There is a need to establish large data sets to support the development of energy expenditure algorithms, and increase the accuracy of activity monitors in energy expenditure estimation has been identified [44].

*Questionnaires.* There is wide variation in the outputs available from questionnaires. Some attribute arbitrary units of measurement to physical activity, whereas some attempt to provide a comparative parameter such as MET-min/day. It is important to note that the more algorithms applied to the data the more indirect the measurement of physical activity. This position statement is not able to provide an answer to this as it is likely to be questionnaire-specific. We recommend that a standardised questionnaire should be used in preference to an in-house questionnaire.

*Diaries.* Some diaries attribute arbitrary units of measurement to physical activity, whereas others attempt to classify physical activity using a comparative parameter such as MET-min/day. It is important to note that the more algorithms applied to the data the more indirect the measurement of physical activity. This position statement is not able to provide a specific answer to this as it is likely to be based on the rationale for using the diary i.e. whether its use is to explore motivation, or adherence to the prescribed intervention.

## 4. Consideration of an important treatment effect for motion sensors, questionnaires and diaries

*Motion sensors.* Any physical activity dimension (energy expenditure, step count, time spent in physical activity in different intensities, time spent sedentary) will be influenced by the device and characteristics of the specific CF population (mild versus severe disease) and the target of the intervention. For all the above dimensions there is no clear consensus on what represents an important treatment effect or the likely timeframe for change to occur. To facilitate consensus on a clinically important difference in physical activity more information on reliability and responsiveness is needed.

*Questionnaires.* This position statement is unable to answer this. Available studies have not yet established an important treatment effect, or the likely timeframe for change to occur and these are likely to be questionnaire-specific.

*Diaries.* This question is not applicable to diaries.

## 2. Summary

This position statement uses the available data on clinimetric properties to inform the current choice of physical activity

tools used within CF research and clinical settings to facilitate physical activity measurement. There are several options for both objective and subjective assessment of physical activity, and the current position of the Exercise Working Group relating to physical activity assessment is summarised below:

#### Motion sensors

- The activity monitor devices with the most available data are SenseWear and ActiGraph. The SenseWear and ActiGraph represent informed choices for activity monitoring in CF. This would be in agreement with the recommendations of the PRO-ACTIVE consortium [45].
- For activity monitors output relating to physical activity dimensions including energy expenditure, step count and time spent in different intensities including sedentary time should be considered in order to provide a comprehensive assessment of physical activity.
- The pedometer with the most available data in CF is the DigiWalker. The DigiWalker currently represents the most informed choice for a pedometer as there is some information on the clinimetric properties.

#### Questionnaires

- The questionnaire with the most available data was the HAES. The HAES currently represents an informed choice to measure physical activity via questionnaire.
- Questionnaires are useful to screen physical activity levels and generate discussion on physical activity patterns.
- Questionnaires should not be used as primary outcome measures without fully assessing their clinimetric properties. They may be useful as a secondary outcome measure or in larger epidemiological studies.

#### Diaries

- There is insufficient data to recommend the use of one diary over another. Diaries are useful to screen physical activity levels and generate discussion on physical activity patterns.

### 3. Future research

The Exercise Working Group agreed on priority areas for future research for physical activity assessment in CF. There is a need to explore the clinimetric properties of current and new technologies for the assessment of physical activity across the age range and the disease trajectory in CF. Clinimetric properties can differ depending on the population being studied and it is impossible to extrapolate findings from one group of patients to another. It is also important that when substantially different versions of existing models of motion sensors or software are available that research is conducted into their clinimetric properties. Bridging studies are also required to establish physical activity measurement as a surrogate of treatment effects. Agreement on the optimal methods of reporting objective physical activity data (i.e. which dimensions and units) and cut-offs for categorising physical activity intensity and daily step counts in CF are needed. The CF

community could refer to the methodology of other initiatives such as the COMET (Core Outcome Measures in Effectiveness Trials) initiative to facilitate development of “core outcome sets” which could then be reported as a minimum in all research on physical activity in CF, making it easier to compare or combine results. Finally the link between physical activity and exercise capacity in CF needs to be further explored.

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#### Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jcf.2015.05.011>.

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